Know Your Options

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When your newborn is discharged from the hospital s/he goes home with more than well wishes from the doctors and nurses. Since November 1998, when Massachusetts passed the Universal Newborn Hearing Screening law, each baby also goes home with a first hearing screening. Out of every one thousand births, three or four newborns will be affected by some degree of hearing loss. Early identification of hearing loss gives families time to adjust to the diagnosis and to learn about the communication options for their child. Early identification also gives the family time to get to know their baby and the baby has time to show the family which communication choice may be best for him/her.

If your baby does not pass the Newborn Hearing Screening, you will be referred to a Department of Public Health approved diagnostic center for a hearing test. An audiologist will perform the painless hearing test to determine whether or not your baby has a hearing loss. The screening is just a part of the diagnostic process, so it is important that all babies that do not pass their screening receive this important follow-up. The hearing test will give you a more definite result and you will be notified of your child's degree of loss, if identified, immediately following the test. The audiologist can also explain how much hearing your baby has (approximately 95% of children born deaf have some residual hearing). Your child's pediatrician should be notified of the screening and testing results. Additionally, families should consult specialists that may include an ear, nose and throat (ENT) specialist, an audiologist and possibly a geneticist. The geneticist can help you determine if the deafness is part of a larger genetic syndrome or possibly linked to a known genetic component of deafness.

It is often said that deafness is a "controversial disability" which proves to be true when you begin to explore the many different methodologies for speech and language development, and education. It is easy to become overwhelmed with all the choices, particularly because most parents of deaf children have had little or no experience with deafness. Surprisingly, the majority of deaf children are born to hearing parents, approximately 90%.

This article describes the choices parents will consider when their child is diagnosed as deaf or hard of hearing. It is important to remember that whichever choice is made, it needs to be right for your entire family and that everyone, including your early intervention provider, must be ready to support that choice.

COMMUNICATION CHOICES

Let's look at the choices: Auditory-Verbal Approach, Bilingual-Bicultural Approach, Cued Speech, Oral Approach and Total Communication. Of course, all choices should be explained to the family and researched by the family (two excellent books are listed at the end of this article), but the type of hearing loss and degree of hearing loss may also, in part, determine the final choice. Families are encouraged to consult with audiologists, early intervention professionals and specialty providers for deaf and hard of hearing children about the following options to make a well-educated and informed choice. *These choices are listed in alphabetical order and should, in no way, imply an order of preferences or effectiveness.*

Auditory-Verbal Approach

Once the child has appropriate amplification (either hearing aids or a cochlear implant) an Auditory-Verbal Therapist works with the parents and child to teach listening in a natural environment. This form of therapy places emphasis on listening skills.

Bilingual-Bicultural Approach

American Sign Language (which is a visual modality) consists of hand signs, body movements, facial expressions and gestures, is the primary language for this approach. English is taught as a second language through reading and writing. This approach is commonly called Bi-Bi and teaches the child and the family about Deaf culture, history and accomplishments of Deaf people.

Cued Speech
Cued Speech is not a language but a use of hand shapes to help with speech reading (also known as lip reading). The hand shapes are based on the sounds the letters make and placed in different locations along with natural mouth movements. The person speaking will do the handshapes (as they speak) to help the deaf recipient understand the speaker.

Oral Approach
The Oral method requires the child to use spoken language and face-to-face communication. Teachers involved with the Oral Approach use hearing (with use of a cochlear implant or hearing aids) and vision to teach the deaf child to speak and listen.

Total Communication
Total Communication is often known as TC or Combined Option. The goal of Total Communication is to use whatever works, often simultaneously, which includes sign, speech, speech reading and gestures. When sign language and speech are used simultaneously (in English word order) it is called "Sign supported English."

AMPLIFICATION CHOICES
Technology choices may be faced, depending on the method chosen. The current choices are:

Hearing Aids
If the child has a hearing loss in both ears, the child will receive two hearing aids (binaural amplification). The benefits of this will be to localize sound, hear environmental sounds, and make speech accessible to the child. More than likely the hearing aids will be behind-the-ear aids that connect to the ear with an earmold in the ear. Infants at just a few months of age can be amplified with hearing aids.

Cochlear Implants
This is the most advanced technology for hearing loss since hearing aids. The cochlear implant involves surgery. Unlike hearing aids, the implant works in the inner ear. The internal portion of the implant is surgically implanted under the scalp. The external portion, the microphone, is attached to the internal portion and has a wire attached to a processor that is worn at waist level or behind the ear. Currently, the U.S. Food and Drug Administration has given approval for infants at 12 months of age to be implanted.

REMEMBER IT'S A FAMILY CHOICE
Families may make an initial communication choice only to realize it is not working for their child and family. It is important to know that it is okay to "change." Learning more about communication choices for your child that is deaf or hard of hearing takes time and effort. Whatever the choice, a good language base is important for your child to learn and grow.

After a diagnosis is made you will be referred to an early intervention program in your geographic area. The early intervention program will become a team with you and your child. As a team you will gain knowledge of your child's deafness. Your team will develop an Individualized Family Service Plan (IFSP). This important document will identify your goals and expectations for your child. The early intervention staff will help you write reasonable expectations. An important goal is to help your child's language grow with the communication choice that has been made. Early intervention staff will be there to support you with your choice. Your early intervention program can arrange for you to be connected with a specialty service provider, which is a professional with expertise in the field of deafness.

Most importantly, a valuable resource for families is another family of a deaf or hard of hearing child. Again, early intervention programs may have support groups with other families or introduce families to one another. Just remember to get connected and "know your options."

Martha A. deHahn is the Parent Outreach Specialist with the Universal Newborn Hearing Screening Program. Martha and her husband Chris have two children, Patrick and Catherine. Both Patrick and Catherine are profoundly deaf. To help Martha write this article she referred to the first book she read when her son was first diagnosed. Choices in Deafness-- A Parent's Guide, Edited by Sue Schwartz, Ph.D. Martha highly recommends this book, along with its Second Edition Choices in Deafness-- A Parents' Guide to Communication Options. Martha can be reached at the Department of Public Health, Northampton, MA office at 800-445-1255 Voice
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Updated 09/29/03